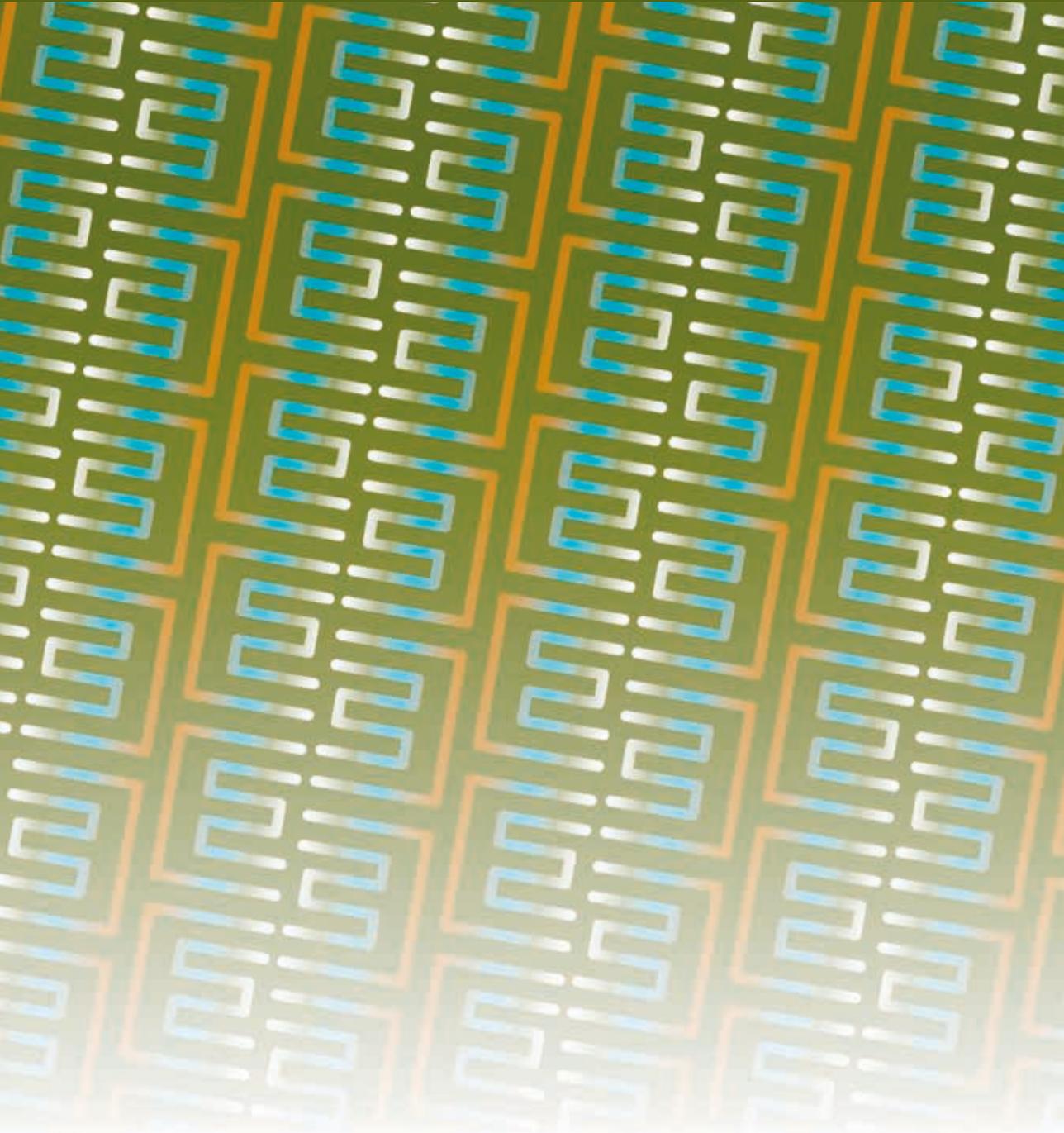


REGIONAL
EUTHANASIA
REVIEW COMMITTEES



ANNUAL REPORT 2017





ANNUAL REPORT 2017

Note on the translation

The RTEs' aim in providing this translation is to allow an international audience insight into the practice of euthanasia in the Netherlands. For reasons of economy, several sections of the annual report dealing with the RTEs' procedures and organisation have not been included in the translation, as well as a number of illustrative cases and several cases in which the committee found that the physician had not acted with due care. All omissions have been indicated in the text. These findings can be found (in Dutch) on the website of the RTEs (www.euthanasiecommissie.nl/uitspraken-en-uitleg).

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FOREWORD

PUBLIC DEBATE

From the perspective of the Regional Euthanasia Review Committees (RTEs), 2017 was a year in which conflicting views came to the fore.

On the one hand, the third evaluation of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act'), published in May 2017, painted a positive picture of public support for euthanasia and of how the process works in the Netherlands.

On the other hand, earlier in the year a number of physicians published a manifesto in which they argued against euthanasia for patients in a very advanced stage of dementia, based on a previously drawn up advance directive. In their opinion, euthanasia is only justified if the patient is still able to express the request for euthanasia orally.

In addition, in autumn 2017 a number of psychiatrists publicly called into question the practice of euthanasia in cases involving patients with a psychiatric disorder. Whether a psychiatric patient who requests euthanasia is decisionally competent and has exhausted all treatment options is a question that, in their opinion, can often only be answered by the attending psychiatrist. And with regard to the review procedures, the evaluation paid a number of compliments, but also provided recommendations on improvements that could be made.

As in previous years, the vast majority of notifications reviewed by the RTEs concerned patients suffering from incurable conditions who could be given only palliative care (care aimed at improving quality of life). These cases concerned patients suffering from cancer, neurological disorders, cardiovascular disease, pulmonary diseases, early-stage dementia, a combination of these conditions, or multiple geriatric syndromes.

Only a very small proportion of the notifications received relate to cases involving patients with a psychiatric disorder and patients in a very advanced stage of dementia, the issues which are the subject of public debate. In 2017 a total of 6,585 notifications were received, of which three concerned patients in a very advanced stage of dementia, and 83 involved patients with a psychiatric disorder. Such cases are unquestionably complex and their review by the RTEs

involves thorough study and discussion of every element of the case files. If questions remain with regard to the notification, the physician who performed euthanasia is asked to attend a committee meeting and provide a further explanation. At the end of 2017 it was decided that with regard to all notifications of euthanasia performed on the basis of an advance directive and involving patients in a very advanced stage of dementia, the notifying physician would be asked to attend a committee meeting and provide further information on the decision-making process and the performance of euthanasia. It is worth noting in this respect that of the 15 physicians who are members of the RTEs, two are psychiatrists, three are elderly-care specialists and one is a clinical geriatrician.

In the debate on what value should be attached to an advance directive drawn up when the patient was still decisionally competent, the RTEs are sometimes – curiously enough – implicitly reproached for adhering to the relevant section of the Act. Section 2 (2) of the Act stipulates that if a patient aged sixteen or over who is no longer capable of expressing his will has made a written declaration requesting that his life be terminated, the physician may comply with this request. If the RTEs were to categorically refuse to find that physicians in such cases had acted with due care, they could rightly be blamed for not adhering to the task given to them by the legislator (to assess whether a physician has acted in accordance with the due care criteria set out in the Act, including the provisions of section 2 (2) of the Act).

The idea that, in cases involving patients with a psychiatric disorder, the physician who performs euthanasia must be the attending psychiatrist is not in line with what has been stipulated by the legislator. No such requirement can be inferred from either the text of the Act or its parliamentary history. Nor do the new draft guidelines of the Dutch psychiatry association (*Nederlandse Vereniging voor Psychiatrie*) indicate that the profession is of the opinion that euthanasia should only be performed by the attending psychiatrist. In line with the Act, case law and the RTEs' findings, however, the physician must, if the request for euthanasia is based on mental suffering, consult an independent psychiatrist in addition to the independent physician required by the Act. The independent psychiatrist should give an independent opinion on, in particular, the patient's decisional competence regarding the request for euthanasia, the lack of any prospect of improvement and whether there is indeed no reasonable alternative. In order to avoid placing an unnecessary burden on the patient, it might be preferable to consult an independent physician (or SCEN physician) who is a qualified psychiatrist.¹

1 This last consideration is also set out in the Euthanasia Code 2018.

THIRD EVALUATION OF THE TERMINATION OF LIFE ON REQUEST AND ASSISTED SUICIDE (REVIEW PROCEDURES) ACT

(included in part)

In line with the arguments put forward in the RTEs' 2016 annual report, the third evaluation of the Act² recommended further investigation into the possibility of introducing appeal in cassation in the interests of the uniform application of the law against the findings of the RTEs. Currently, this recommendation is highly relevant in view of the Public Prosecution Service's decision, prompted by findings of the RTEs, to launch for the first time since the Act came into force in 2002 preliminary judicial investigations into cases from 2016 and 2017.

Jacob Kohnstamm LL.M

Coordinating chair of the Regional Euthanasia Review Committees

The Hague, March 2018



MALE-FEMALE RATIO

Male	3384
Female	3201

CHAPTER I

DEVELOPMENTS IN 2017

1 ANNUAL REPORT

For more information on the outline of the Act, the committees' procedures, etc., see the Euthanasia Code 2018 and <https://english.euthanasiecommissie.nl>.

In their annual report, the Regional Euthanasia Review Committees (RTEs) report on their work over the past calendar year and thus account for the way in which they have fulfilled their statutory task: reviewing notifications of termination of life on request and assisted suicide on the basis of the due care criteria laid down in the Act. This report uses the term 'euthanasia' to refer to both forms of termination of life. The distinction between termination of life on request and assisted suicide is made only where necessary.

Another aim of the annual report is to give physicians and other interested parties insight into the way in which the committees have reviewed and assessed specific notifications. A large part of the report is therefore devoted to descriptions of various cases.

We have aimed to make the annual report accessible to a wider public by avoiding the use of legal and medical terms as much as possible, or by explaining them where necessary.

9

2 NOTIFICATIONS

Number of notifications

The breakdown of the number of notifications of euthanasia in the five separate regions can be found on the website (www.euthanasiecommissie.nl/uitspraken-en-uitleg (in Dutch)).

In 2017 the RTEs received 6,585 notifications of euthanasia, two of which came from the Caribbean part of the Netherlands (Bonaire, St Eustatius and Saba). This is 4.4% of the total number of people who died in the Netherlands in that year (150,027). In 2016 the RTEs received 6,091 notifications, which was 4% of the total number of deaths (148,973). The number of notifications of euthanasia has thus risen, but remains a relatively small proportion of the total number of deaths in the Netherlands.

Male/female ratio

The numbers of male and female patients were almost the same: 3,384 men (51.4%) and 3,201 women (48.6%).



RATIO BETWEEN CASES OF TERMINATION OF LIFE ON REQUEST AND CASES OF ASSISTED SUICIDE

10

● Termination of life on request	6303
● Assisted suicide	250
● Combination of the two	29

Ratio between cases of termination of life on request and cases of assisted suicide

There were 6,306 cases of termination of life on request (over 95.8% of the total), 250 cases of assisted suicide (3.8%) and 29 cases involving a combination of the two (0.4%).

Nature of conditions

Most common conditions

More than 89.4% of cases (5,893) concerned patients with incurable cancer, neurological disorders (such as Parkinson's disease, multiple sclerosis and motor neurone disease), cardiovascular disease, pulmonary disease or a combination of these conditions. The exact numbers were: 4,236 (cancer), 782 (combination of conditions), 374 (neurological disorders), 275 (cardiovascular disease) and 226 (pulmonary disease).

Dementia

Three notifications involved patients in an advanced or very advanced stage of dementia who were no longer able to communicate regarding their request and in whose cases the advance directive was decisive in establishing the voluntariness of the request. See, for instance, case 2017-14, described in Chapter II.

In 166 cases the patient's suffering was caused by early-stage dementia. The patients were at a stage where they still had insight into the condition and its symptoms (loss of bearings and personality changes). They were deemed decisionally competent with regard to their request because they could still grasp its implications. Case 2017-06, described in Chapter II, is an example.

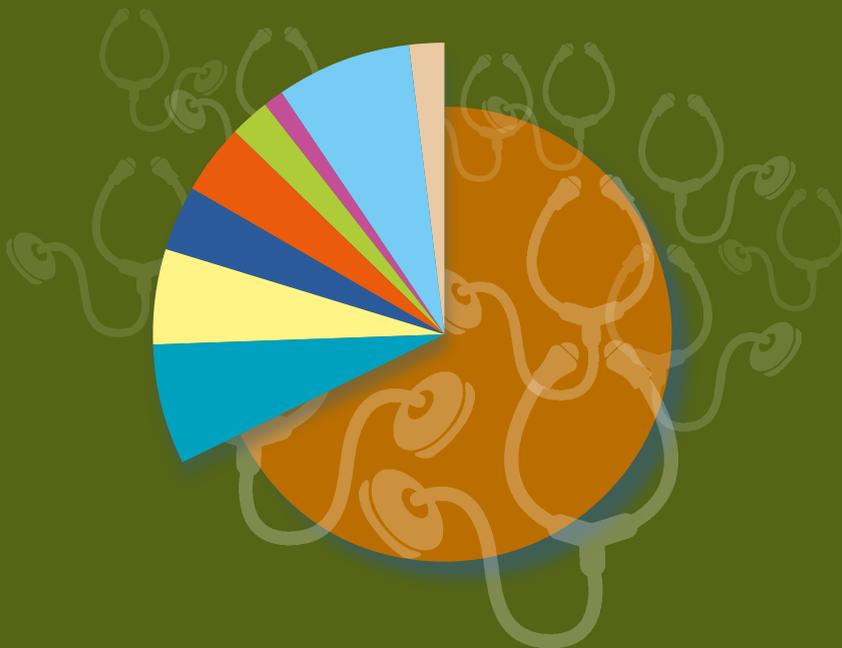
Psychiatric disorders

In 83 notified cases of euthanasia the patient's suffering was caused by a psychiatric disorder. In 36 of these 83 cases the notifying physician was a psychiatrist, in 22 cases a general practitioner, in six cases an elderly-care specialist and in 19 cases another physician (for instance a psychiatry registrar). In these cases, particular caution should be exercised, as was done in case 2017-42 (described in Chapter II). The 2009 guidelines of the Dutch psychiatry association (*Nederlandse Vereniging voor Psychiatrie*) 'Dealing with requests for assisted suicide from patients with a psychiatric disorder' describe the procedures psychiatrists should follow if one of their patients requests euthanasia.³

For points to consider regarding patients with dementia, see page 42 of the Euthanasia Code 2018.

For points to consider regarding patients with a psychiatric disorder, see page 40 of the Euthanasia Code 2018.

3 These guidelines and other information on this subject can be found (in Dutch) on the association's website (www.nvvp.net/website/onderwerpen/detail/euthanasie).



DISORDERS INVOLVED IN 2017

12

● Cancer	4236
● Neurological disorders	374
● Cardiovascular disease	275
● Pulmonary disorders	226
● Multiple geriatric syndromes	293
● Dementia	169
<i>early-stage dementia: 166</i>	
<i>(very) advanced stage of dementia: 3</i>	
● Psychiatric disorders	83
● Combination of disorders	782
● Other conditions	147

The NVVP has announced that it intends to produce a revised version of the guidelines in 2018.

Multiple geriatric syndromes

For points to consider regarding multiple geriatric syndromes, see page 21 of the Euthanasia Code 2018.

Multiple geriatric syndromes – such as sight impairment, hearing impairment, osteoporosis, osteoarthritis, balance problems or cognitive deterioration – may cause unbearable suffering without prospect of improvement. These syndromes, which are often degenerative in nature, generally occur in elderly patients. It is the sum of these problems, in conjunction with the patient's medical history, life history, personality, values and stamina, that may give rise to suffering which that particular patient experiences as being unbearable and without prospect of improvement. In 2017 the RTEs received 293 notifications of euthanasia that fell into this category.

Combination of conditions; other conditions

782 cases involved a combination of conditions. This category comprises all notifications that involve a combination of conditions from the above-mentioned categories; for example, the patient's suffering is caused by both cancer and cardiovascular disease, or by dementia or a psychiatric disorder in combination with COPD.

Lastly, the RTEs register cases involving conditions that do not fall into any of the above categories, such as chronic pain syndrome, as 'other conditions'. There were 147 such cases in 2017.

13

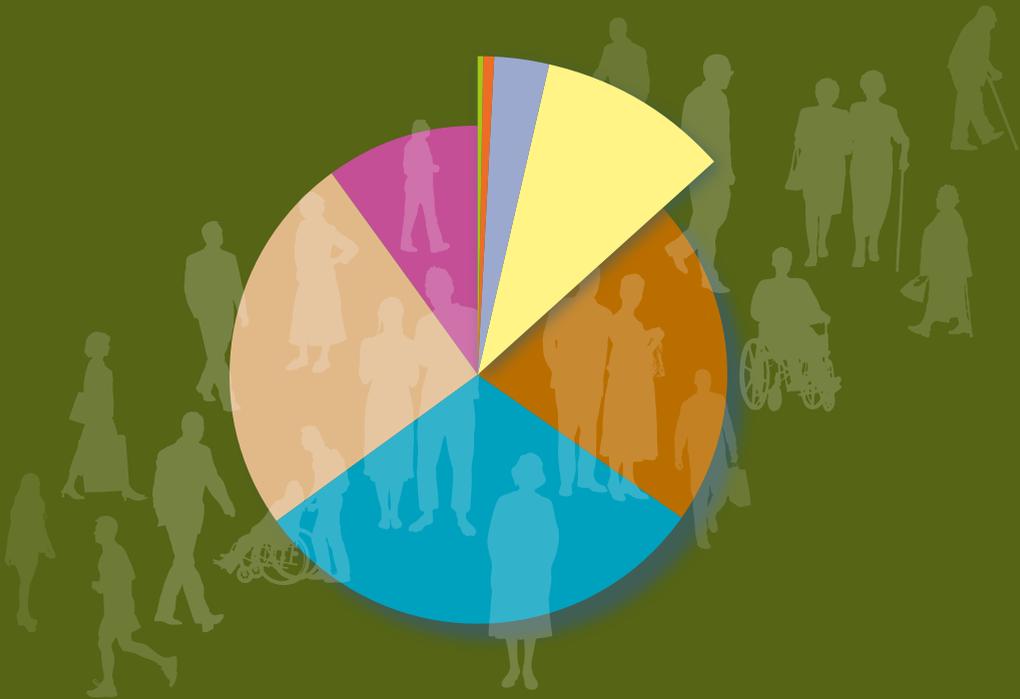
Age

For points to consider regarding minors, see page 40 of the Euthanasia Code.

The highest number of notifications of euthanasia involved people in their seventies (2,002 cases, 30.4%), followed by people in their eighties (1,634 cases, 24.8%) and people in their sixties (1,405 cases, 21.3%).

In 2017 the RTEs received three notifications of euthanasia involving a minor between the ages of 12 and 17.

There were 73 notifications concerning people aged between 18 and 40. In 46 of these cases, the patient's suffering was caused by cancer and in 13 cases it was caused by a psychiatric disorder. In the categories 'dementia' and 'psychiatric disorders', the highest number of notifications involved people in their eighties (63 cases) and people in their fifties (16 cases), respectively. In the category 'multiple geriatric syndromes' the largest number of notifications concerned people aged 90 or older (199 cases).



AGE

● 30 years or younger*	22
● 30-40 years	51
● 40-50 years	183
● 50-60 years	635
● 60-70 years	1405
● 70-80 years	2002
● 80-90 years	1634
● 90 years or older	653

* including 3 minors

Locations

In the vast majority of cases (5,308 cases, 80.6%) euthanasia was performed at the patient's home. Other locations were a hospice (436 cases, 6.6%), a care home (286 cases, 4.3%), a nursing home (287 cases, 3.8%), a hospital (172 cases, 2.6%) or elsewhere, for instance at the home of a family member, in a sheltered accommodation centre or a convalescent home (96 cases, 1.5%).

Notifying physicians

The vast majority of cases (5,636) were notified by a general practitioner (85% of the total number). The other notifying physicians were elderly-care specialists (382), other specialists (247) and registrars (68). There was also a large group of physicians with other backgrounds (252), most of them physicians affiliated with the End-of-Life Clinic (SLK).

The number of notifications by physicians affiliated with the SLK grew from 487 in 2016 to 751 in 2017, an increase of 54%.

As is apparent from the notification details, SLK physicians are often called upon in complex cases, at the request of the attending physician or otherwise. Many of the notifications of cases involving a psychiatric disorder came from SLK physicians: 52 out of 83 notifications (more than 62%). Of all the notifications of cases in which the patient's suffering was caused by a form of dementia, 57 (over 33%) came from SLK physicians. Of the notifications involving patients with multiple geriatric syndromes, 108 (37%) came from SLK physicians. The records show that physicians may find these cases complex or that physicians refer patients to the SLK for reasons of principle. Some physicians will only perform euthanasia if the patient has a terminal condition. They, too, sometimes refer patients to the SLK.

Euthanasia and organ and tissue donation

Voluntary termination of life by means of euthanasia does not necessarily preclude organ and tissue donation. The *Richtlijn Orgaandonatie na euthanasie* [Guidelines on organ donation after euthanasia] published by the Dutch Foundation for Transplants (July 2017) provides a step-by-step procedure for such cases.⁴ In 2017 the RTEs received four notifications indicating that organ donation had taken place after euthanasia. Case 2017-86 (Chapter II) is an example.

4 The guidelines and their background and underlying arguments can be found (in Dutch) at www.transplantatiestichting.nl/bestel-en-download/richtlijn-orgaandonatie-na-euthanasie.



NOTIFYING PHYSICIANS

16

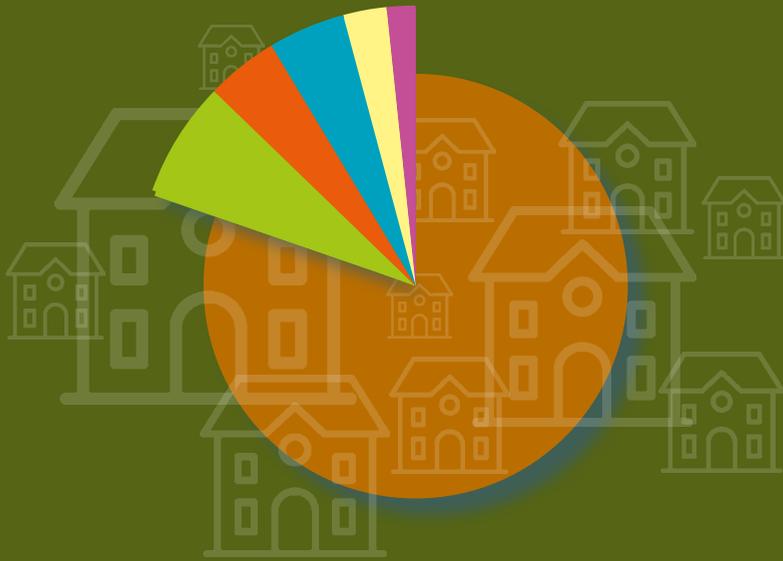
● General practitioner	5636
● Elderly-care specialist	382
● Specialist working in a hospital	247
● Registrar	68
● Other physician (e.g. doctors affiliated with the End-of-Life Clinic)	252

Due care criteria not complied with

In 12 of the 6,585 notified cases, the RTEs found that the physician who performed euthanasia did not comply with all the due care criteria set out in section 2 (1) of the Act: that is 0.18% of all notifications. Just over half of these cases concerned the procedural criteria of consulting an independent physician (one case) and due medical care (six cases). Four of the other five cases concerned the criteria of a voluntary, well-considered request, unbearable suffering without prospect of improvement and no reasonable alternative, usually in combination. The remaining case was one in which the physician did not meet the additional requirement in cases involving patients with a psychiatric disorder: consulting an independent psychiatrist who should, in particular, assess whether the patient is decisionally competent regarding the request, whether the patient's suffering is unbearable and whether there are no reasonable alternatives.

'Grey areas' in the review procedure

(not included here)



LOCATIONS

● Home	5308
● Hospice	436
● Care home	286
● Nursing home	287
● Hospital	172
● Elsewhere	96

(for instance at the home of a family member, in a sheltered accommodation centre or a convalescent home)

3 COMMITTEE PROCEDURES – DEVELOPMENTS

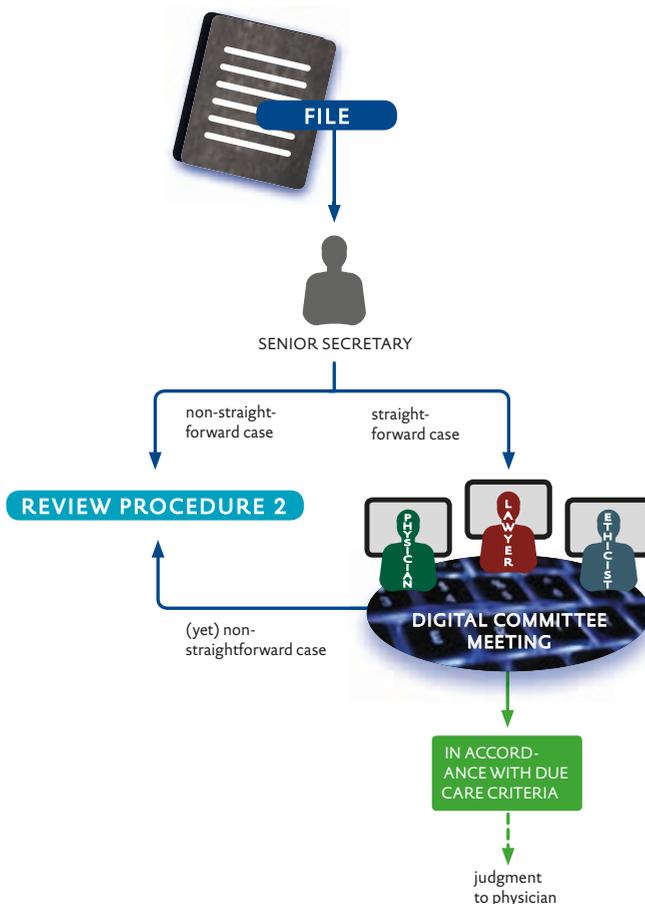
Straightforward and non-straightforward cases

In 2012 the RTEs began categorising the notifications immediately upon receipt as ‘straightforward’ and ‘non-straightforward’ cases. Straightforward cases and the accompanying files are sent digitally to the committee – which consists of a lawyer, a physician and an expert on ethical or moral issues – on a weekly basis, so that these notifications can be handled within the appropriate timeframe. In 2017, 81% of the notifications received concerned straightforward cases.

Notifications are considered straightforward if the committee secretary, who is an experienced lawyer, can establish that the

REVIEW PROCEDURE 1

± 80% OF THE NOTIFICATIONS
(STRAIGHTFORWARD CASES)



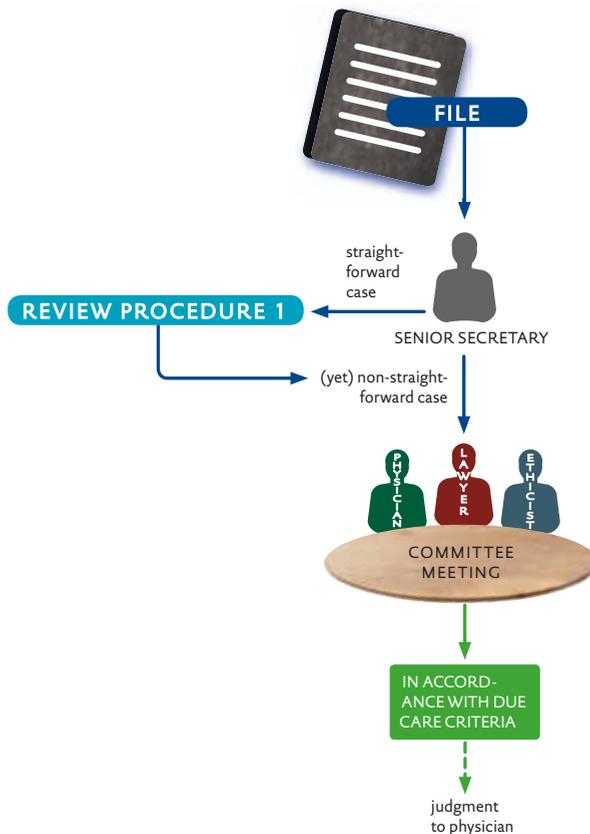
information provided is so comprehensive and the likelihood that the physician has complied with the statutory due care criteria is so great that the committee will be able to review the notification digitally. Cases 2017-68, 2017-84, 2017-49 and 2017-59 have been included in Chapter II as examples of such straightforward cases.

A small number of notifications that were initially considered straightforward (92 cases, 1.4% of the total number of notifications) were later deemed to be non-straightforward, and as a result were discussed in a committee meeting. The arrangement is that if any of the committee members thinks that a straightforward case does raise questions it is referred to the monthly committee meeting for discussion.

The other 19% of the notifications received raised questions that required discussion in person (for instance because of a complex context such as psychiatric disorders or dementia, or because the

REVIEW PROCEDURE 2

± 19% OF THE NOTIFICATIONS
(NON-STRAIGHTFORWARD CASES)

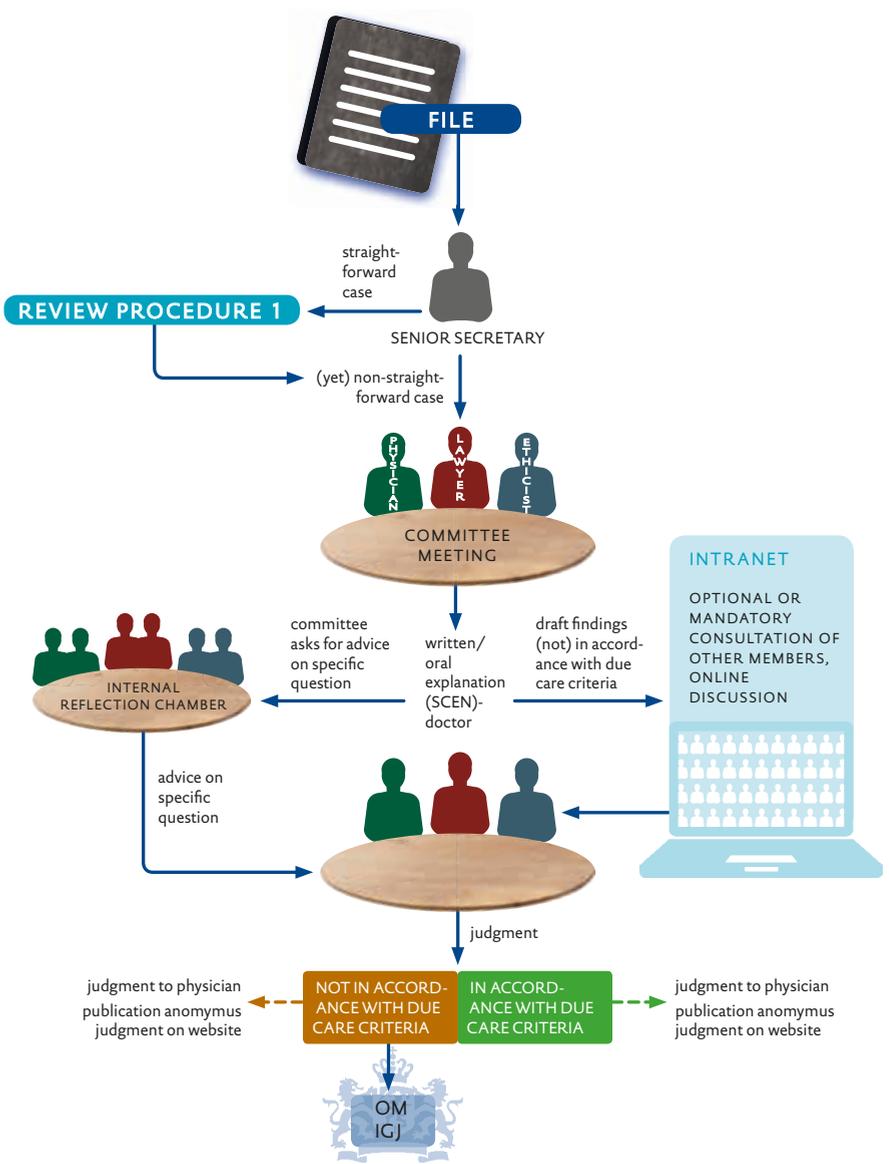


information submitted by the physician was insufficient) and were reviewed at the monthly committee meetings.

In 2017 the RTEs dealt with 5,765 notifications in this manner (87.6% of the total number of notifications). The average time that elapsed between the notification being received and the findings being sent to the physician was 52 days, somewhat longer than the time limit of six weeks laid down in section 9 of the Act.

REVIEW PROCEDURE 3

± 1% OF THE NOTIFICATIONS (NON-STRAIGHTFORWARD CASES)



Complex cases

(not included here)

Euthanasia Code 2018

In spring 2018, a revised version of the 2015 Code of Practice will be published, entitled 'Euthanasia Code 2018. Review Procedures in Practice'. The Euthanasia Code 2018 outlines the aspects that the RTEs regard as relevant in connection with their statutory task. Its aim is to provide a clear explanation – particularly for physicians performing euthanasia and for independent physicians – of how the RTEs apply and interpret the statutory due care criteria.

Reflection chamber

(not included here)

Letter containing findings

(not included here)

Organisation

(not included here)

CHAPTER II

CASES

II

1 INTRODUCTION

The text of the Act and relevant sections of the Criminal Code and the Burial and Cremation Act can be found at <https://english.euthanasiecommissie.nl>

This chapter describes various findings by the RTEs. The essence of the RTEs' work consists of reviewing physicians' notifications concerning termination of life on request and assisted suicide (euthanasia).

A physician who has performed euthanasia is required by law to report this to the municipal pathologist, who then forwards the notification and the accompanying documents to the RTEs. The main documents in the notification file submitted by physicians are the report by the notifying physician, the report by the independent physician consulted, excerpts from the patient's medical records, the patient's advance directive if there is one and a declaration by the municipal pathologist. The independent physician is almost always contacted through the Euthanasia in the Netherlands Support and Assessment Programme (SCEN), which falls under the Royal Dutch Medical Association (KNMG).

The committees examine whether the notifying physician has acted in accordance with the six due care criteria set out in section 2 (1) of the Act.

The due care criteria say that the physician must:

- a. be satisfied that the patient's request is voluntary and well considered;
- b. be satisfied that the patient's suffering is unbearable, with no prospect of improvement;
- c. have informed the patient about his situation and his prognosis;
- d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;
- e. have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;
- f. have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.

The RTEs review notifications in the context of the Act, its legislative history and the relevant case law. They also take previous committee findings into account, as well as the decisions of the Public Prosecution Service and the Health Care Inspectorate (as of 1 October 2017, the new Health and Youth Care Inspectorate (IG)).

The RTEs decide whether *it has been established* that the criteria of (c) informing the patient, (e) consulting an independent physician, and (f) due medical care have been fulfilled. This involves what Dutch lawyers refer to as a ‘full review’.

As regards the three due care criteria of (a) a voluntary and well-considered request, (b) unbearable suffering without prospect of improvement and (d) no reasonable alternative, the physician must *plausibly argue* that, given the circumstances of the case, he was *reasonably able to conclude* that they had been fulfilled. The way in which compliance with these three criteria is assessed would be described by Dutch lawyers as a ‘limited review’ or a test of reasonableness. It means the RTEs do not carry out a full review of compliance with the due care criteria and therefore do not re-examine the same issues as the physician who made the original decision. The RTEs cannot do this, as the patient is no longer alive: these are the issues that the independent physician will have focused on.

The cases described in this chapter fall into two categories: cases in which the RTEs found that the due care criteria had been complied with (section 2) and cases in which the RTEs found that the due care criteria had not been complied with (section 3). The latter means that in the view of the committee in question, the physician did not comply with one or more of the due care criteria.

Section 2 is divided into three subsections. In subsection 2.1 we present five cases that are representative of the vast majority of the notifications received by the RTEs. These are cases involving incurable conditions, such as cancer, neurological disorders, cardiovascular disease or pulmonary disease.

In subsection 2.2 we examine the various statutory due care criteria, in particular (a) a voluntary and well-considered request, (b) unbearable suffering without prospect of improvement, (d) no reasonable alternative, and (f) due medical care. In this subsection we present cases that are more complex, and therefore include more information about the patient, their request and the nature of their suffering, and more details on the committee’s considerations. There is no separate discussion of two of the due care criteria: (c) informing the patient about his prognosis and (e) consulting at least one independent physician. The criterion under (c) is generally closely connected with other due care criteria, including the criterion that the request must be voluntary and well considered. This can only be the case if the patient is well aware of his health situation and of his prognosis. The due care criterion concerning consultation (e) is relevant to the cases in which it was found that the due care criteria were not complied with.

Lastly, in subsection 2.3 we describe a number of cases of euthanasia or assisted suicide involving patients in a special category: patients with a psychiatric disorder (one case), patients with dementia (two cases) and patients with multiple geriatric syndromes (two cases).

In all the cases described in section 2, the committee found that the physician had complied with the due care criteria laid down in the Act.

Section 3 describes 10 out of the total of 12 cases in which the committee found that the due care criteria had *not* been met. This concerns two cases in which the committee found that the physician had not complied with the criterion of a voluntary and well-considered request *and* the criterion of unbearable suffering without prospect of improvement (2017-73 and 2017-103); two cases in which the committee found that the criterion of unbearable suffering without prospect of improvement had not been met (2017-31 and 2017-79); and one in which the physician had not exercised the greater degree of caution required in euthanasia cases involving psychiatric patients (2017-24). There were seven cases in which one of the more procedural criteria had not been complied with, i.e. consultation (2017-10) and due medical care (six cases, four of which are described in section 3: 2017-02, 2017-11, 2017-28 and 2017-118).

Each case has a number. These numbers can be used to find the full text of the findings (in Dutch) on the RTEs' website (www.euthanasiecommissie.nl).

2. PHYSICIAN ACTED IN ACCORDANCE WITH THE DUE CARE CRITERIA

2.1 Five representative cases

As stated in chapter 1, the vast majority of euthanasia cases involve patients with cancer, neurological disorders, cardiovascular disease and pulmonary disease. The following five cases are examples (all are straightforward cases).

In the first case we have included almost the entire text of the finding, to give the reader an idea of what RTE findings look like. Details that could be traced to individuals have been omitted. Together, the five cases illustrate the issues that the RTEs encounter most frequently. Three of the cases have an additional, more unusual feature, such as early consultation, the combination of euthanasia and organ donation, and a patient whose main place of residence was abroad.

CASE 2017-68 CANCER

See case 2017-68 on the website for the full text (in Dutch).

FINDING: due care criteria complied with

KEY POINTS: straightforward notification; early consultation because metastases in the brain meant there was a danger of the patient losing the ability to communicate in the near future.

FACTS AND CIRCUMSTANCES

The reports of the notifying physician and the independent physician, and other documentation received, revealed the following.

a. Nature of the patient's suffering, informing the patient, and alternatives

The patient, a man in his seventies, was diagnosed with severe skin cancer eight years before his death. He had received treatment for his condition. Four months before his death metastases were found in the lungs and brain. In the month before his death the patient had an epileptic fit, after which his condition deteriorated rapidly. His condition was incurable. He could only be treated palliatively (care aimed at improving the patient's quality of life).

The patient's suffering consisted of confusion, drowsiness and urinary and faecal incontinence. He was also suffering from an increasing inability to communicate. There was nothing he was capable of doing: he could hardly walk by himself, had become bedridden and was completely

dependent on others for his personal care. He knew that only further deterioration would follow and was suffering from the futility of his situation, the absence of any prospect of improvement, the loss of quality of life and his further physical decline.

The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion.

There were no alternative ways to alleviate his suffering that were acceptable to the patient. The documents made it clear that the physician and the specialists had given him sufficient information about his situation and prognosis.

b. Request for euthanasia

The patient had discussed euthanasia with the physician before. Three days before his death, the patient asked the physician to actually perform the procedure to terminate his life. The physician concluded that the request was voluntary and well considered.

c. Consulting an independent physician

The physician twice consulted the same independent physician, who was also a SCEN physician. In the first consultation, the independent physician saw the patient around two months before euthanasia was performed, after having been informed of the patient's situation by the physician and examining his medical records. This early consultation took place because there was a danger of the metastases in the brain making communication impossible in the near future.

In her report the independent physician gave a summary of the patient's medical history and the nature of his suffering. She concluded, partly on the basis of her interview with the patient, that the due care criteria had not been met. The patient was not yet suffering unbearably and no specific request for euthanasia had been made.

The independent physician saw the patient a second time one day before the procedure to terminate his life, after having been informed by the physician of developments in the patient's condition since her first visit. In her second report the independent physician gave a summary of these developments. In her report of this second visit the independent physician concluded that the due care criteria had been complied with. The patient was now suffering unbearably and a specific request for euthanasia had been made.

d. The procedure

The physician performed the termination of life on request using the method, substances and dosage recommended in the KNMG/KNMP's Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide, published in August 2012.⁵

ASSESSMENT

The committee examines retrospectively whether the physician acted in accordance with the statutory due care criteria laid down in section 2 of the Act. In view of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well considered and that his suffering was unbearable, with no prospect of improvement. The physician informed the patient sufficiently about his situation and his prognosis. Together, the physician and the patient could be satisfied that there was no reasonable alternative in the patient's situation. The physician consulted at least one other, independent physician, who saw the patient and gave a written opinion on whether the due care criteria had been complied with. The physician performed the euthanasia with due medical care.

DECISION

The physician acted in accordance with the due care criteria laid down in section 2 (1) of the Act.

CASE 2017-84

(not included here)

CASE 2017-86 NEUROLOGICAL DISORDER

FINDING: due care criteria complied with

KEY POINTS: straightforward notification; euthanasia in combination with organ donation

The patient, a woman in her fifties, was diagnosed two years before her death with motor neurone disease (a disease that leads to the death of nerve cells in the spinal cord and in part of the brain). Her condition was incurable. She could only be treated palliatively (care aimed at improving the patient's quality of life).

See case 2017-86 on the website for the full text (in Dutch).

⁵ These guidelines can be found at <https://www.knmg.nl/advies-richtlijnen/knmg-publicaties/publications-in-english.htm>.

The patient's suffering consisted of the increasing deterioration in her situation. She was experiencing severe loss of function. She could no longer eat, nor could she communicate clearly. The patient, who had always been independent, active and communicative, was entirely dependent on others and hardly able to do anything for herself. She knew there was no prospect of improvement in her situation and that the only prognosis was deterioration. She experienced her suffering as unbearable.

The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion. The physician concluded that the request was voluntary and well considered. He also consulted an independent (SCEN) physician, who concluded that the due care criteria had been complied with.

The patient wanted to donate her organs. After consultation, she was placed under sedation at home and a tube was inserted into her windpipe so she could be given oxygen. She was then taken to hospital, where euthanasia was performed.

The committee found that the physician had acted in accordance with the due care criteria.

CASE 2017-49 PULMONARY DISEASE

See case 2017-49 on the website for the full text (in Dutch).

FINDING: due care criteria complied with

KEY POINTS: straightforward notification

The patient, a woman in her fifties, had been suffering for 14 years from chronic narrowing of the airways (chronic obstructive pulmonary disease, or COPD). Her lung disease progressed until it was very severe. Her condition was incurable. She could only be treated palliatively (care aimed at improving the patient's quality of life).

The patient was suffering from general malaise, shortness of breath, muscular complaints and fatigue. She had always been an independent woman but she was now increasingly confined to her bed. She was dependent on oxygen and had to rely on others for her personal care. The patient was suffering from the futility of her situation, the lack of quality of life and a fear of suffocating. She experienced her suffering as unbearable.

The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion. The physician concluded that the request was voluntary and well considered. He also consulted an independent (SCEN) physician, who concluded that the due care criteria had been complied with. The physician performed the euthanasia with due medical care.

The committee found that the physician had acted in accordance with the due care criteria.

CASE 2017-59 CARDIOVASCULAR DISEASE

FINDING: due care criteria complied with

KEY POINTS: straightforward notification

See case 2017-59 on the website for the full text (in Dutch).

The patient, a woman in her eighties, developed heart failure five months before her death. Her condition was incurable and became terminal. She could only be treated palliatively (care aimed at improving the patient's quality of life).

The patient's suffering was caused by severe shortness of breath at the slightest exertion, and by her immobility and exhaustion. She also experienced intense itching and back pain. There was nothing the patient was capable of doing and she had become confined to her sofa. She suffered from a fear of falling and from the futility of her situation. She experienced her suffering as unbearable.

The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion. The physician concluded that the request was voluntary and well considered. He also consulted an independent (SCEN) physician, who concluded that the due care criteria had been complied with. The physician performed the euthanasia with due medical care.

The committee found that the physician had acted in accordance with the due care criteria.

2.2 Four cases illustrating one of the due care criteria in the Act

VOLUNTARY AND WELL-CONSIDERED REQUEST

For general points regarding the voluntary and well-considered request, see pages 17 ff of the Euthanasia Code 2018.

See case 2017-12 on the website for the full text (in Dutch).

For points to consider regarding the advance directive, see pages 36 ff of the Euthanasia Code 2018.

The Act states that the physician must be satisfied that the patient's request is voluntary and well considered. A written request is not required by law, but in some cases it can be helpful if there is a request in writing, as illustrated by the following case.

CASE 2017-12

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification; case involving a patient in a state of reduced consciousness; advance directive

The patient, a woman in her sixties who had been living with cancer and its effects for years, was again diagnosed with recurrent lung cancer six months before her death. The cancer was accompanied by pleurisy and doctors suspected that her lymphatic vessels had been damaged. Her condition deteriorated rapidly in the final days before her death. Her suffering consisted of increasing pain, shortness of breath and confinement to her bed. She suffered from the loss of quality of life and the fact that her condition could only deteriorate further. She experienced her suffering as unbearable.

The patient had discussed euthanasia with the physician before. About a year before her death she had handed the physician an advance directive. Three days before her death, the patient asked the physician to actually perform the procedure to terminate her life. The physician concluded that the request was voluntary and well considered.

The physician consulted an independent physician who was also a SCEN physician. The independent physician saw the patient on the day euthanasia was performed, after he had been told about her situation by the attending physician and had examined her medical records. At the time of his visit, the patient was no longer able to communicate. The independent physician saw that the patient was extremely emaciated, was gasping for breath and that her face was tensed and contorted. He got the impression that she was suffering continuously and without prospect of improvement. As the patient could no longer communicate her request, her advance directive was decisive in the independent physician's assessment of whether her request was voluntary and well considered. In his report he concluded that the due care criteria had been complied with.

The committee found that the physician could be satisfied that the patient's request was voluntary and well considered and that she was suffering unbearably with no prospect of improvement. Although it was impossible to communicate with the patient when euthanasia was performed, she did show signs of unbearable suffering. As stated in the Euthanasia Code 2018 (p. 46), in such cases euthanasia can be performed despite the fact that the patient is in a state of reduced consciousness.

As regards the consultation, the committee considered that it was apparent from the documents that at the time of the consultation it was no longer possible to communicate with the patient. However, the independent physician established that there were signs of unbearable suffering and he was satisfied that the patient had previously expressly stated that she did not want to experience such suffering. Section 3.6 of the Euthanasia Code 2018 states that the criterion of consulting an independent physician can still be met, even if communication with the patient is no longer possible at the time of the independent physician's visit. The independent physician will then have to base his opinion regarding the due care criteria on information from the physician, the advance directive, the medical records and information from other sources.

The committee found that the physician had acted in accordance with the due care criteria.

UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT

For general points regarding unbearable suffering without prospect of improvement, see pages 20 ff of the Euthanasia Code 2018.

The physician must be satisfied that the patient is suffering unbearably and that there is no prospect of improvement. There is seldom only one dimension to the burden of suffering experienced by the patient. In practice, it is almost always a combination of aspects, including the absence of any prospect of improvement, which determines whether suffering is unbearable. The physician must therefore investigate all aspects that together make the patient's suffering unbearable.

CASE 2017-07

See case 2017-07 on the website for the full text (in Dutch).

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification; establishing the unbearable nature of suffering can be very difficult

The patient, a woman in her eighties, had suffered from dizziness for four years. She constantly felt light-headed and movement, particularly turning, caused her to feel nauseous. Three years before her death, she was diagnosed with an inner ear disorder on both sides. She experienced persistent problems because of severely impaired automatic balance control, including orientation and gaze stabilisation. Typical problems included fluctuating visual acuity, reduced balance control with an increased risk of falling, sudden fatigue, and nausea when looking at moving images. Three years before her death she suffered a heart attack and eighteen months before her death she was fitted with a pacemaker. In the last six months before her death her functioning deteriorated considerably. Around three months before her death, the patient had her pacemaker turned off and stopped taking medication, except for medication to help her sleep.

The patient's suffering consisted of the progressive deterioration in her functioning. Performing activities of daily living cost her an increasing amount of time and effort. She felt very restricted by her balance problems and the fact that she tired quickly. She always had to be careful when turning round. She had to move her head slowly, otherwise she would feel ill and nauseous. She fell down regularly. She was no longer able to do several things that were very important to her, such as going for walks in the countryside, walking to the supermarket and doing her own shopping, reading books, listening to music, and participating in social occasions. She experienced less and less joy in life.

The patient had always been a lively and sociable person, and attached great value to her independence. She was suffering from her physical decline, the loss of joy in life, not being able to enjoy social relationships with other people, and the imminent loss of independence. She experienced her suffering as unbearable.

The patient had discussed euthanasia with her general practitioner before. The latter was unwilling to grant her request for euthanasia, because she found it difficult to establish the unbearable nature of the patient's suffering and felt pressured by the patient. The patient then contacted the End-of-Life Clinic (SLK). The physician, together with an SLK nurse, spoke with the patient on three occasions. At first, the

physician had difficulty establishing the unbearable nature of her suffering, mainly because of the cheerful manner in which the patient presented herself. The woman tried to emphasise the positive aspects of her situation and dismiss the misery. She characterised herself as someone who knew how to act decisively, showed great willpower, was optimistic and resilient, had few needs and was not quick to complain. It was precisely these characteristics that made it difficult for the patient to describe her unbearable suffering. Nonetheless, by the time of their third meeting, the physician was satisfied that her suffering was unbearable.

According to the SCEN physician consulted, the crucial question was whether a person who could still do so much and appeared so energetic could be said to be suffering unbearably. The patient made it clear to him that she herself experienced her suffering as unbearable. This was caused mainly by the progressive loss of function and the loss of her enjoyment of life. She could still appear to be enjoying life, but no longer experienced the feeling that went with it. The independent physician was able to understand the patient's request for euthanasia and concluded, albeit it somewhat hesitantly, that her suffering was unbearable.

The committee noted the following in connection with the unbearable nature of the patient's suffering. At first, the physician doubted whether the patient was suffering unbearably, because of the cheerful and optimistic manner in which she presented herself. After speaking with the patient several times and consulting with colleagues, the physician gradually became convinced that the social isolation and the loss of any meaningful way to spend her time, which resulted from her deafness and dizziness, constituted unbearable suffering for the patient. She had led an intellectually rich and independent life, and that was now ending in a situation marked by anxiety because of dependence, danger of falling, isolation and the prospect of further debilitation.

In view of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well considered, and that her suffering was unbearable, with no prospect of improvement. The other due care criteria were also fulfilled, in the committee's view.

NO REASONABLE ALTERNATIVE

The absence of a reasonable alternative, a due care criterion which must be seen in relation to suffering with no prospect of improvement, is discussed on pages 24 ff of the Euthanasia Code 2018.

The physician and the patient must together come to the conclusion that there is no reasonable alternative in the patient's situation. If there are less drastic ways of ending or considerably reducing the patient's suffering, these must be given preference. In the case described below, only experimental forms of treatment remained for a young patient with a very extensive history of mental health problems. The committee found that there was no reasonable alternative available.

See case 2017-08 on the website for the full text (in Dutch).

CASE 2017-08

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification; no reasonable alternative

The patient, a woman aged between 18 and 30, had a very extensive history of mental illness, with persistent symptoms of extremely low spirits (depression), complicated by a chronic eating disorder and an obsessive-compulsive personality disorder. The eating disorder led to various physical symptoms, such as emaciation, debilitation, fatigue and osteoporosis. She also suffered from a genetic connective tissue disorder that particularly affected her joints and skin.

The patient was trapped between her eating rituals and untreatable low spirits. She felt as if she had died five years previously; since then she just felt like an empty husk. She said the emptiness was 'filled' by the eating disorder. She was not interested in anything and hardly had the energy to undertake any activity. Most of her time was taken up by her eating and vomiting rituals. Her physical deterioration also played a part: she was underweight, and felt tired and dizzy. And although she had creative talents and was interested in animal care, she hardly had any opportunity to pursue these hobbies due to her eating rituals and their undermining effects on her health. In the end, her physical condition deteriorated rapidly. According to the patient, she was suffering the most from her depression.

The patient had been treated for her depression in hospital and at home, with all types of medication, talk therapy and ECT (electroconvulsive therapy, whereby the patient is anaesthetised and an electric current is passed across the brain through electrode patches). She received intensive treatment (counselling) for the eating disorder in specialised clinics. The patient cooperated actively with all forms of treatment offered. The treatments had a positive but temporary effect on her eating disorders and her depression. After the treatment and/or her stay in a

clinic ended, however, both problems soon returned. The patient's condition was incurable. All that remained was experimental forms of treatment. Therefore, despite her youth, there were no longer any realistic treatment options available to her.

Around four months before the termination of life, the physician asked an independent psychiatrist to assess whether the patient's suffering was without prospect of improvement and to assess possible treatment alternatives. This independent psychiatrist established, as had those who treated the patient previously, that she was severely dysfunctional in all aspects of life and that her situation was characterised by a hopelessness and lack of prospect of improvement that had led to her sustained and consistent wish to die. The depression did not respond to treatment in accordance with protocol, and this led the independent psychiatrist to suspect that the patient had a genetic vulnerability.

The independent physician, too, was of the opinion that the patient was suffering unbearably without prospect of improvement. He saw a young woman with severe mental illness. She had tried in many ways to improve her mental health, but to no avail. He concluded that the due care criteria had been complied with.

The committee noted the following as regards the existence of a reasonable alternative: since her early youth, the patient had been treated exhaustively for both her eating disorder and her depression. Despite her extreme youth, there were no more realistic treatment options available. The independent physician and the independent psychiatrist confirmed the physician's assessment that further treatment would not result in any lasting improvement and that there were no longer any realistic alternatives for her. The other due care criteria were also fulfilled, in the committee's view.

DUE MEDICAL CARE

For more information on due medical care, see pages 33 ff of the Euthanasia Code 2018

The physician must exercise due medical care in performing euthanasia. Two aspects of this are the substances and doses administered, and appropriate checks to determine the depth of the induced coma. In assessing this due care criterion, the RTEs refer to the KNMG/KNMP 'Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide' of 2012. The case described below shows that if the physician deviates from the guidelines, this does not necessarily mean that the criterion of due medical care has not been complied with.

CASE 2017-82

See case 2017-82 on the website for the full text (in Dutch).

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification; muscle relaxant not administered as the patient was already deceased

The physician performed euthanasia by administering 2,000mg of thiopental. The patient died almost immediately after. Because the physician had established that the patient was deceased, he did not administer the muscle relaxant.

The committee found that the physician had exercised due medical care.

2.3 Cases concerning people with a psychiatric disorder, dementia or multiple geriatric syndromes

PSYCHIATRIC DISORDER

For points to consider regarding patients with a psychiatric disorder, see pages 40 ff of the Euthanasia Code 2018.

Termination of life on request and assisted suicide are not restricted to patients in the terminal phase of their life. People with a longer life expectancy, such as psychiatric patients, may also be eligible. However, physicians must exercise particular caution in such cases. This means that they must consult an independent psychiatrist or other expert, mainly in order to obtain an opinion on the patient's decisional competence regarding their request for euthanasia, the lack of prospect of improvement and whether there is indeed no reasonable alternative.

CASE 2017-42

See case 2017-42 on the website for the full text (in Dutch).

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification; particular caution in cases involving patients with a psychiatric disorder

The patient, a man in his sixties, had been suffering from a mood disorder since his late teens. As a young man he had been admitted to institutions for long periods of time. He also received prolonged outpatient treatment. Many pharmaceutical therapies were tried, which were either unsuccessful or had too many side effects. Five years before the patient's death, he was admitted to an institution after attempting suicide, and underwent ECT (electroconvulsive therapy, whereby the patient is anaesthetised and an electric current is passed across the brain through electrode patches). After 10 of the 12 scheduled treatments he said he wanted to stop, because he was not experiencing any improvement. He could not be motivated to undergo other forms of treatment. For years, he had cooperated with all treatment, without there being any improvement.

The patient's suffering consisted of constant anxiety. He spent his days almost entirely in his room or on the balcony and only dared go outside in the evening. Whenever he went outside he suffered from feelings of paranoia and delusions of reference (when an everyday or coincidental event is believed to have a personal meaning). As a result he became socially isolated. In addition, the patient was permanently unable to adapt to unavoidable changes in situations or to give purpose to his life. The man had never been able to get used to having moved into sheltered housing and the fact that his job at a sheltered workshop came to an end. As he grew older, the expectation was that he would become increasingly dependent on others for his personal care, which would

place ever greater demands on his social adaptability. This was unbearable to him. The patient experienced his suffering as unbearable. The physician was satisfied that his suffering was unbearable and without prospect of improvement according to prevailing medical opinion.

Around six weeks before the patient's death the physician consulted an independent psychiatrist. She asked him how he would diagnose the patient, whether this diagnosis matched what was indicated in the records, and whether there were any treatment options left for the patient. The independent psychiatrist concluded that the primary diagnosis (schizoaffective disorder) was correct and that there were also several chronic psychotic features (a condition whereby a person's grasp of reality is severely impaired; they may, for instance, see images or hear voices that are not there). According to the independent psychiatrist there were still some treatment options, but given the patient's history they had little chance of success and the prognosis was therefore poor. The independent psychiatrist considered the patient to be decisionally competent regarding his request for euthanasia.

The physician consulted an independent physician who was also a SCEN physician. The independent physician also considered the patient to be decisionally competent regarding his request for euthanasia. The independent physician concluded that the due care criteria had been complied with.

The committee noted that physicians must exercise particular caution when dealing with a euthanasia request from a patient suffering from a psychiatric disorder. The committee found that in the case under review the physician, who was a psychiatrist, did so. Besides the independent SCEN physician, the physician also consulted an independent psychiatrist. The psychiatrist considered the patient to be decisionally competent regarding his request for euthanasia and was of the opinion that the available alternatives to relieve suffering would not work for this patient.

The committee found that the physician could be satisfied that the patient's request was voluntary and well considered and that he was suffering unbearably with no prospect of improvement. The other due care criteria were also fulfilled, in the committee's view.

DEMENTIA

For points to consider regarding patients with dementia, see pages 42 ff of the Euthanasia Code 2018.

There is a distinction to be made between the following situations: euthanasia for a patient with early-stage dementia (the phase in which the patient generally still has insight into the disease and the symptoms, such as loss of bearings and personality changes); euthanasia for a patient in a later phase of dementia, where it is uncertain whether they are still decisionally competent regarding their request; and euthanasia for a patient in whom the disease has progressed to the point that the patient is no longer able to request euthanasia. In the latter two situations, an advance directive may take the place of a request for euthanasia.

CASE 2017-06

(not included here)

CASE 2017-14 ADVANCED-STAGE DEMENTIA

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification; disagreement among specialists consulted

The patient, a woman in her eighties, was diagnosed three years before her death with a dementia syndrome that most closely resembled Alzheimer's disease. Her condition was incurable. The patient had a dedicated care worker who provided advice and support, and she had moved into a care home. In the final period before her death, her dementia had reached such an advanced stage that admission to a secure, psychogeriatric ward was deemed necessary. The patient was utterly opposed to this idea, and she repeatedly threatened to jump out of the window if she was moved.

Her suffering consisted of increasing loss of memory and grasp of the world around her. She suffered severely from the prospect of being admitted to a secure ward and thus losing her independence. This prospect led to increased anxiety and irritability. She associated being placed in a secure ward with traumatic experiences she had gone through in the war and she did not want to lose her freedom again. Having to go into such a ward was the absolute limit for her. If that were to happen, also given her experience of close family members with dementia, she would not want to go on living.

Around 20 years before her death, the patient had drawn up an advance

See case 2017-14 on the website for the full text (in Dutch).

directive for the first time. Two years before her death, she drew up a new advance directive concerning her mental condition as well as her physical deterioration.

On the basis of his conversations with the patient, the physician established that she was very resolute in her refusal to go into a secure ward, and that she was also very resolute in her wish for euthanasia. He had been told by the head of care of the ward where she was staying that the patient had already said two years previously, during her intake interview, that she would never want to go into a secure ward. The patient had discussed this regularly with her since then.

About a month before the patient's death, at the physician's request, an independent elderly-care specialist examined the patient to assess her decisional competence. According to the elderly-care specialist, the patient appeared to have no insight into her disease, prognosis and disabilities. She seemed to have no oversight of the situation or insight into the relevant issues. He considered her to be decisionally incompetent in terms of overseeing complex issues and taking decisions on such issues.

The physician consulted an independent physician who was also a SCEN physician and a geriatric psychiatrist. According to the independent physician, the patient did not have a psychotic disorder or a mood disorder, and had a powerful need for control and independence, partly due to her traumatic war experiences. She was no longer able to understand the complexity of her situation. However, if the subject was put to her in a calm manner, she was able to indicate clearly that she wanted to retain her freedom, that she did not want to be placed in a secure ward, and that she did not want to suffer any further debilitation. At this point, she understood the situation sufficiently and was consistent in her wishes, according to the independent physician. The latter concluded that the patient was decisionally competent regarding her request for euthanasia, and her request was voluntary and well considered.

The committee considers that a request for termination of life from a patient suffering from progressive dementia must be responded to with even greater caution than usual. There may be doubts about whether the patient is decisionally competent, and in view of the nature of the condition, whether the request is voluntary and well considered. It may also be unclear whether the patient's suffering is in fact unbearable.

In the committee's opinion, the physician exercised sufficient caution in this case. The physician consulted an independent elderly-care specialist,

as well as an independent physician who was also a geriatric psychiatrist. Both gave their opinion on the patient's decisional competence. The elderly-care specialist considered her incompetent with regard to making decisions on complex issues. The independent physician, on the other hand, was of the opinion that she was decisionally competent regarding her request for euthanasia. In view of the independent physician's extensive substantiation of his opinion, compared to the more cursory substantiation given by the elderly-care specialist, and in view of the conversations the physician had with the patient, the committee found that the physician could consider the opinion of the independent physician/geriatric psychiatrist to be more convincing and that he could reasonably conclude that the patient was decisionally competent regarding her request.

The committee found that the physician could be satisfied that the patient's request was voluntary and well considered and that she was suffering unbearably with no prospect of improvement. The other due care criteria were also fulfilled.

MULTIPLE GERIATRIC SYNDROMES

*See pages 21 ff
and 51 of the
Euthanasia Code
2018.*

For a patient's request for euthanasia to be considered, his suffering must have a medical dimension. However, it is not a requirement that there be a *life-threatening* medical condition. Multiple geriatric syndromes – such as sight impairment, hearing impairment, osteoporosis, osteoarthritis, balance problems or cognitive deterioration – may cause unbearable suffering without prospect of improvement.

These syndromes, which are often degenerative in nature, generally occur in elderly patients. It is the sum of these problems, in conjunction with the patient's medical history, life history, personality, values and stamina, that may give rise to suffering which that particular patient experiences as being unbearable and without prospect of improvement. Two such cases are described below.

CASE 2017-38

See case 2017-38 on the website for the full text (in Dutch).

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification; independent physician gives negative assessment, but physician proceeds with euthanasia nonetheless

The patient, a woman in her eighties, was suffering from severe fatigue, as well as wear and tear in several joints and osteoporosis. As a result, six months before her death, she broke her kneecap after a fall. The patient also suffered from age-related hearing loss (she was deaf in her right ear and had 60% hearing loss in her left ear). She had undergone two cataract operations. In the end she was blind in her left eye and her sight was impaired in her right eye. She also had mild cognitive impairments. After her fall, the patient followed a rehabilitation programme in hospital and was allowed to go home after she had learnt to climb stairs again. She became increasingly frail, particularly after this period. Her general practitioner, the attending elderly-care specialist during the rehabilitation programme, and the independent geriatrician consulted by her general practitioner were of the opinion that the patient's problems would not improve.

The patient's suffering consisted of intense fatigue, increasing loss of hearing, loss of sight, dizziness and pain occurring every day in almost all her joints. She lost weight and became increasingly frail. She had difficulty walking and was unsteady on her feet. She was afraid of falling but refused to use a rollator, which she considered a loss of dignity. Her impaired hearing was an obstacle to her social interactions and due to her cognitive deterioration she could no longer pursue her hobbies the way she used to. As a result there were few activities from which she could still derive satisfaction and self-respect. The patient, who had always been a very independent woman, found it terrible that she could no longer be the person she had always been. She suffered mostly from the prospect of even greater dependence. She had already had a taste of that when she broke her kneecap. She had hated the period in hospital and the rehabilitation process. She did not want to experience further debilitation. She longed for her life to end. The patient experienced her suffering as unbearable. The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion.

The physician and the general practitioner together decided to have further tests carried out by, among others, a vascular surgeon, a rheumatologist and an ear, nose and throat specialist. The physician also

consulted an independent clinical geriatrician. The latter suspected there was a 'completed life issue', possibly with depression contributing to the suffering. At the recommendation of this geriatrician, the patient had briefly taken antidepressants to improve her mood. This medication did not have a positive result, and caused too many side effects. The patient did not think she was depressed. It was suggested that she move into a more sheltered living environment, but she was utterly opposed to the idea. None of the physicians involved could see any viable alternative treatment options.

Although the independent physician established that the patient was having to make an increasing number of concessions and was experiencing very serious problems, he still felt that the issue was more a feeling of 'completed life' based on the patient's experience of her disabilities rather than unbearable suffering. However, he believed that other medically related problems might emerge in the near future which would lead to unbearable suffering that was palpable to him. As it stood, he was unable to grasp the unbearable nature of the patient's suffering sufficiently. The independent physician therefore concluded that the due care criteria had not been fulfilled.

In response to the independent physician's negative assessment, the physician wrote on the model reporting form that she had initially been misled by the almost 90-year-old patient's relatively youthful appearance, her well-kept house and her way with words. The patient always tried to keep up appearances. It had taken many conversations to convince the physician that the patient was suffering unbearably. As time went by, the medical dimension of her suffering became more evident. Frailty and fatigue began to play an increasing role. The independent physician spoke with the patient only once, and compared the unbearable nature of her suffering with the suffering of other very elderly patients, and did not view it in light of this patient's specific personality. The physician spoke extensively with the independent physician. She understood the independent physician's reasoning, but felt it would be unfair to the patient to wait until additional physical suffering occurred, for instance caused by a cerebral infarction (stroke).

The physician decided not to consult a second independent physician because the required consultation had already taken place and because she felt she was sufficiently able to substantiate her opinion and explain the difference between her view and that of the independent physician. The physician considered that a second independent physician would probably also be unable to penetrate the patient's façade. The physician was convinced that the patient was suffering unbearably from a

combination of conditions with a clear medical dimension, which she had difficulty dealing with due to her personality.

The committee noted that the physician was guided by the patient's substantiated request and her own conviction, which developed over time, that the patient was indeed suffering unbearably without prospect of improvement. Physicians may disregard a negative assessment by the independent physician and proceed with euthanasia. According to the Act the physician is responsible, but will have to explain clearly why he or she disregarded the independent physician's assessment. The committee found that the physician explained extensively and convincingly in her reports why she became convinced that the patient's suffering was unbearable to her and without prospect of improvement, and that there were no reasonable alternatives to reduce the suffering. In view of the above facts and circumstances, the committee found that the due care criteria had been complied with in this case.

CASE 2017-19

(not included here)

3. PHYSICIAN DID NOT ACT IN ACCORDANCE WITH THE DUE CARE CRITERIA

Cases in which the RTEs find that the physician has not acted in accordance with the due care criteria always lead to lengthier findings than other cases. This is because a conclusion cannot be reached in such cases without giving the physician the opportunity to give an oral explanation.

In the year under review, the RTEs found in 12 cases that the physician had not acted in accordance with all the due care criteria in performing euthanasia or assisting with suicide. Eleven of these are discussed below, in the order in which the relevant due care criteria are listed in the Act.

NON-COMPLIANCE WITH THE CRITERIA OF VOLUNTARY AND WELL-CONSIDERED REQUEST AND UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT

For information on voluntary and well-considered requests, see pages 17 ff of the Euthanasia Code 2018 and on unbearable suffering without prospect of improvement, see pp. 20 ff.

It is possible for a patient to fall into a coma or a state of reduced consciousness shortly before the intended time that euthanasia is to be performed. If, as in the following case, the patient spontaneously falls into a state of reduced consciousness from which he cannot be aroused and shows signs of possible suffering, the physician may perform euthanasia. If there are no signs that the patient may be suffering, euthanasia cannot be performed. If such a situation occurs before the patient has been seen by the independent physician, the latter will have to base his opinion regarding the request on information from other sources (the physician, advance directive, the medical records etc.) With regard to the patient's suffering he will have to base his assessment on his own observations, as well as the medical records and information provided orally by others. This difficult situation is illustrated by the following case.

CASE 2017-73

See case 2017-73 on the website for the full text (in Dutch).

FINDING: due care criteria not complied with

KEY POINTS: non-straightforward notification; voluntary and well-considered request; advance directive; unbearable suffering

The patient, a woman in her seventies, had been diagnosed in early March 2017 with metastasised cancer of the head of the pancreas. The patient's condition was incurable. The patient could only be treated palliatively (care aimed at improving quality of life).

The patient's suffering consisted of extreme fatigue, increasing dependency on others and the fact that she was bedridden. She was nauseous and could not eat or drink properly. The patient, whose husband had died shortly before, was suffering from her rapid decline. She experienced that suffering as unbearable. The physician was satisfied that the patient's suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion.

The patient first discussed euthanasia with her physician in the autumn of 2016, together with her husband, who was ill. They had both said that if they were in unbearable pain and were bedridden, had no quality of life and were expected to die in the near future, they would want no further treatment except sedation or euthanasia. In early January 2017, the patient confirmed this wish. After learning of her diagnosis, the patient discussed euthanasia with the physician on several occasions. Just over two weeks before her death, the patient asked the physician to actually perform the procedure to terminate her life. She later repeated her request.

Two days before the termination of life, the patient fell into a coma, due to a major cerebral infarction (stroke). The evening before the termination of life and shortly before the procedure was carried out, the patient briefly displayed improved consciousness. When asked by the physician whether she indeed wanted euthanasia, she squeezed his hand and nodded vaguely.

The physician concluded that the request was voluntary and well considered. It was clear to the physician that the patient was suffering at that time: she was in pain and she was moaning and crying.

The physician consulted an independent physician who was also a SCEN physician. He saw the patient a day before she died. The independent physician noted that the patient was responding when spoken to, but

that in his assessment she was unable to respond to questions. According to him she did not appear to be in pain, and there was no shortness of breath or discomfort. The unbearable nature of her suffering – although impossible to assess now according to the independent physician – consisted of loss of independence and the fact she was bedridden. In his report, the independent physician concluded, partly on the basis of the physician notes and conversations with the physician and the patient's children, that the due care criteria had been met.

After studying the details of the notification and a further written explanation by the physician, the committee had additional questions regarding the patient's wishes, her unbearable suffering and her state of consciousness the day before her death. The physician gave a further explanation regarding the patient's background and her wish for euthanasia. The patient was in a turbulent situation: her husband, who had suffered from cancer, had died a few months earlier following a euthanasia procedure. Not long after, she was diagnosed with metastasised cancer of the head of the pancreas. In several conversations between the physician and the patient, she said that she would want euthanasia too. When her husband's request for euthanasia was carried out, she and her children had felt it had been a good process, in which they were able to say goodbye together. According to the physician, the patient did not want to lose her independence. She did not want to become bedridden, suffer unbearable pain and/or experience severe shortness of breath. The euthanasia process had not actually commenced yet, but that was the intention.

Earlier, it had been discussed with the patient that she would draw up an advance directive. It was believed that an advance directive had been drawn up digitally, but due to circumstances (the patient suddenly having to move in with her son; the file probably having been saved on her husband's computer) it could not be produced. According to the children, the advance directive existed. After the cerebral infarction the patient was no longer able to express her wish for euthanasia in words. The patient's children wanted the physician to grant that wish. The physician explained that he had considered palliative sedation and discussed this with the family. Given the unpredictability of her condition, in which it might still be days or even a week before she died, this was not an option for the family. They said this was the opposite of what she would have wanted.

As regards the confirmation of the wish for euthanasia on the evening before euthanasia was performed, the physician was aware that these non-verbal signs were a question of interpretation. However, his view was

that on the basis of these signs he could conclude that the patient actually wanted euthanasia. The physician also indicated that she was sweating and grimacing. He was satisfied that the patient was suffering unbearably and was in pain.

The committee noted that the patient was in an irreversible state of reduced consciousness before the euthanasia process between the physician and the patient started. In order to proceed with euthanasia in such a case, there must at least be an advance directive drawn up by the patient. There must also be signs that the patient may be suffering and the independent physician will have to see the patient (Euthanasia Code 2018, p. 48).

The committee noted from the physician's reports that no advance directive was produced. The committee also noted that the independent physician consulted by the physician saw the patient. However, the independent physician indicated that the patient was unable to express her wish for euthanasia in words, was unable to respond to questions and did not appear to be in pain. The independent physician's findings with regard to the patient's condition did not match those of the physician. The committee considered this difference in observation between the independent physician and the physician to be conceivable in view of the patient's fluctuating state of consciousness.

As regards the communication between the physician and the patient prior to euthanasia being performed, in the interview with the physician it was established that no prior agreement had been made as to how this communication should be interpreted, not even as an introduction to the question. The committee therefore concluded that the nodding and hand squeezing were insufficient in this specific situation to qualify as confirmation of the patient's wish for euthanasia. The fact that there was no underlying advance directive made this all the more problematic.

In view of the above facts and circumstances, the committee found that the physician could not be satisfied that the patient had made a voluntary and well-considered request. The committee also found that the physician's conviction that the patient was suffering unbearably was insufficiently supported by facts or circumstances that were at play in the period shortly before euthanasia was performed.

The physician did not act in accordance with the due care criteria.

ADVANCE DIRECTIVE

For points to consider regarding the advance directive, see pages 36 ff of the Euthanasia Code 2018.

An advance directive may take the place of an oral request (section 2 (2) of the Act). The other due care criteria then apply ‘*mutatis mutandis*’. It is important that the patient indicate as clearly as possible the specific circumstances in which the request should be acted upon. These must be circumstances in which the patient can be said to be suffering unbearably. In the following case, the committee had questions regarding both these criteria.

CASE 2017-103

See case 2017-103 on the website for the full text (in Dutch).

FINDING: due care criteria not complied with

KEY POINTS: non-straightforward notification; advance directive; unbearable suffering without prospect of improvement

The patient, a woman in her sixties, had been suffering since 2007 from forgetfulness, low spirits and feelings of panic. She became increasingly withdrawn. In 2010 she was diagnosed with Alzheimer’s, a progressive disease. In late 2013 the patient was admitted to a care home, where she resided in a small-scale care unit, because she could no longer cope at home. By that time, she no longer had any insight into her situation. The patient had always said to her family that she did not want to be admitted to a nursing home. In the last six months before her death, her condition deteriorated rapidly.

According to the physician, the patient’s suffering was characterised by restlessness and regular shouting and screaming. As a result she could no longer stay in the group. The patient often resisted activities of daily living, including having to be changed repeatedly because of her urinary and faecal incontinence. The patient was now confined to a wheelchair, which meant she could no longer remove herself from situations she experienced as unpleasant. She became increasingly trapped in her own body. All she could do was sit in a chair; she could no longer even eat independently. She would not always let people come near her and sometimes she would become angry. This was a serious problem for her carers; she would hit them, spill food and drink, kick them, and grab them and refuse to let go. There were crying fits and a lot of anger.

According to the physician, the patient’s underlying suffering dominated her life. Like the family and the carers, the physician was convinced, on the basis of the patient’s non-verbal utterances, that her suffering was unbearable to her and without prospect of improvement according to prevailing medical opinion.

According to the patient's children, her first response on learning of her Alzheimer's diagnosis had been, 'Oh no, this is not what I want'. They had often talked about dementia with her, because several members of their family had ended up in a nursing home because of dementia. Their mother thought that was terrible. She had always said that if she ended up with dementia and had to go into a nursing home, she would not want to go on; she would want to die. The patient had discussed euthanasia previously with her general practitioner, who treated her until she went into the care home in 2013. In 2011 she had drawn up an advance directive and handed it to her general practitioner. The patient was still decisionally competent at the time. The patient's advance directive included the following passages: [...] *that I want to prevent both physically and mentally unbearable suffering for myself in all circumstances. As I have been diagnosed with dementia (Alzheimer's) and COPD, both my mental and physical suffering could put me in a situation that is unbearable to me. In this advance directive, I want to record what I do not want to happen. I am competent to do this now. If my mental well-being deteriorates to that degree, I want my specialist [...] to be involved, to reaffirm my wishes as set out in this advance directive. [...] I am completely opposed to being admitted to a nursing home. If that happens I want active euthanasia to be performed. It is important to me to be able to die what I consider a dignified death and if the above-mentioned points are complied with, I trust that this will be possible.*

When she handed over her advance directive in 2011, the patient also asked her general practitioner directly to perform euthanasia. However, the general practitioner refused to grant her request. After this, the patient became increasingly withdrawn and it became difficult for her family to make contact with her. Broaching the subject again was not considered, because the general practitioner's refusal had been so adamant.

When she was staying in the care home, the children decided to discuss her wish for euthanasia with the general practitioner affiliated with the care home. Around four months before the patient's death, this general practitioner contacted the End-of-Life Clinic (SLK) for a second opinion. As the general practitioner did not want to perform euthanasia, the SLK physician took over the case. She visited the patient four times and observed her at different times during the day. She was also informed extensively by the family and the carers.

The physician consulted an independent physician who was also a SCEN physician. The independent physician, an elderly-care specialist, saw the patient more than a month before euthanasia was performed, after he had been told in detail about the patient's situation by the physician and

had examined her medical records. The independent physician concluded that the patient was not suffering unbearably, and that the advance directive was not explicit enough. In his opinion, therefore, the due care criteria had not been complied with.

Following the outcome of the SCEN consultation, the physician considered the independent physician's arguments seriously, discussed them with him in person, and postponed the euthanasia procedure in order to think about it and consult her colleagues at the SLK. The physician decided not to ask a second independent physician for a new assessment, but asked a colleague at the SLK – a clinical geriatrician and SCEN physician – to observe the patient. The physician stated that she wanted to reflect on the case together with a colleague who had experience with this type of patient and whom she knew to be critically minded. This colleague visited the patient around a week and a half before her death. The physician had informed the colleague briefly in person about the patient. The colleague was of the opinion that it was not possible to gain insight into the patient's thoughts or feelings other than by interpreting her non-verbal behaviour, which in itself appeared largely to be driven automatically by external stimuli. Little could be seen of what was going on inside. According to the colleague, in this humiliating situation the patient made a pitiful impression. The physician's substantiation of her decision to perform euthanasia despite the independent physician's negative assessment included the following points:

- *The degree of suffering may vary from one moment to the next. I saw the patient more frequently than the SCEN physician did. My assessment of the patient's suffering was also confirmed by the observations of the care staff, who saw the patient even more often, and the family.*
- *The law requires that the physician be satisfied that the patient's suffering is unbearable, with no prospect of improvement. 'Physician' refers to the physician who performs euthanasia, not the SCEN physician. I was indeed satisfied that the patient was suffering unbearably.*
- *When assessing a patient's suffering, there can always be personal differences in interpretation, as is also clear from the literature [...].*

When asked about how she determined that the patient was suffering unbearably, the physician explained that it was mainly through her observations that she had reached the conclusion that the patient was suffering unbearably. She observed and filmed the patient and later also watched footage taken of the patient receiving care. One of the physician's observations was that the patient would be lying calmly in her bed, and then go completely rigid when the care staff came to help

her. The SLK nurse added that the patient's mood could change suddenly and that she could become very angry. When asked about it, the physician indicated that she interpreted the patient's anger as unbearable suffering. The physician was well aware that it always remains a question of interpretation; patients with dementia are often angry. The physician took account of the patient's prior history in her assessment. When assessing whether the patient was suffering unbearably, the physician also took into account the fact that she had indicated very clearly that she was totally opposed to being admitted to a nursing home because of her dementia. The situation in which she found herself was exactly what she did not want to happen.

According to the physician, the patient was suffering without prospect of improvement and there was no reasonable alternative. The care staff were capable. They knew the patient's situation and knew how to deal with it.

The physician was aware that she and the independent physician held opposing views. When asked about how she interpreted the independent physician's report, the physician answered that the independent physician did not take the views of the family and the care staff into account. The physician disagreed with that. After all, they knew the patient best. The physician indicated that the independent physician could have decided to visit the patient a second time. The physician pointed out that her colleague supported her view on the unbearable nature of the patient's suffering and that the colleague had said so to her. According to the physician, her colleague's report was completely clear and the phrase 'a pitiful impression' was sufficiently clear. If the colleague had not shared her view, the physician would not have performed euthanasia. The physician saw no added value in asking a second independent physician for an assessment.

Asked why the patient's explicit wish for her attending specialist to be involved in the process in order to reaffirm her wishes, as indicated in her advance directive, was not carried out, the physician answered that she had tried to trace the attending specialist but that he no longer worked at the place where he had treated the patient.

The committee noted the following as regards the request being voluntary and well considered.

According to the patient's family members, immediately after she received the Alzheimer's diagnosis, she had said that this was not what she wanted. She also indicated this in her advance directive. It is beyond dispute that the patient was able to make a reasonable appraisal of her

interests when she drew up her advance directive. The question is, however, whether this advance directive – which was several years old and had not been recently updated orally or in writing – was still fully valid. As mentioned on page 36 of the Euthanasia Code 2018, the Act does not limit the validity of an advance directive, nor does it require the directive to be regularly updated. However, the older the directive, the more doubt there may be as to whether it still reflects the patient's actual wishes.

As the patient had not reaffirmed her advance directive orally or in writing since handing it to her general practitioner in 2011, the question is whether the circumstances set out in the advance directive were described specifically enough to constitute a voluntary and well-considered request.

Page 43 of the Euthanasia Code 2018 notes that it is still possible to grant a request for euthanasia at the stage where dementia has progressed to such an extent that the patient is no longer decisionally competent and is no longer able to communicate (or is able to communicate only by simple utterances or gestures), provided the patient drew up an advance directive when still decisionally competent. The directive must be clear, and evidently applicable to the current situation. The physician and the independent physician must consider the entire disease process and any other specific circumstances when assessing the request. They must interpret the patient's behaviour and utterances, both during the disease process and shortly before euthanasia is performed. At that moment the physician must be satisfied that carrying out euthanasia is in line with the patient's advance directive, and that there are no contraindications (such as clear signs that the patient no longer wishes his life to be terminated).

The committee established that the patient indicated in her advance directive that she wanted in all circumstances to prevent both physically and mentally unbearable suffering for herself and that she wanted euthanasia if she had to go into a nursing home. She also stated that she wanted to die with dignity. The committee acknowledged that there may be differences in insight regarding how detailed and specific the description in the advance directive of the circumstances in which the patient wants euthanasia must be, and that views may differ on whether the advance directive was clear enough in the present case. In its assessment of whether there was a voluntary and well-considered request, the committee took particular account of the fact that the patient did not reaffirm the advance directive, drawn up in 2011, in the period before her admission to the care home, neither to her family nor to her then general practitioner and her specialist, and that the physician

never discussed her wish for euthanasia with her. Bearing all of this in mind, the committee considered the content of the advance directive to be insufficient grounds for the physician to be reasonably able to conclude that it expressed the patient's wishes persisting up to the time when she became decisionally incompetent. Another key factor is the fact that the physician did not seek contact with the patient's former general practitioner and her specialist in order to gain an idea of the patient's wishes. The committee therefore found that the physician could not reasonably conclude that in this case there was a voluntary and well-considered request from the patient, as described in section 2 (2) of the Act.

As regards the due care criteria that the physician must be satisfied that the patient is suffering unbearably and without prospect of improvement and that there must be no reasonable alternative, the committee found as follows. To assess whether the patient experienced unbearable suffering, both the physician and the independent physician had to resort to interpretation of her behaviour and her utterances, since she had become decisionally incompetent. The physician indicated that she came to the conclusion that the patient was suffering unbearably mainly on the basis of what she had observed. When assessing whether the patient's suffering was unbearable, the physician also took into account the fact that the patient had indicated very clearly in her advance directive that she was totally opposed to being admitted to a nursing home.

However, the independent physician concluded, on the basis of his visit to the patient and after studying the available video footage, that she was not suffering unbearably, because his observations and the footage showed the opposite to what was being said.

As the physician and the independent physician held opposing views on whether the patient was suffering unbearably, the committee decided to study the video footage. The committee was of the opinion that the footage did not provide unequivocal guidance supporting the physician's assessment that the patient was suffering unbearably. Moreover, the advance directive was rather cursory in its description of what suffering would consist of. The fact that the patient indicated in her advance directive that she wanted euthanasia if she had to go into a nursing home was an insufficient basis for the assumption that she was suffering unbearably. It has to be plausible that the patient actually experienced unbearable suffering, both during the disease process and shortly before euthanasia was performed. As regards the consultation, the committee noted that physicians may disregard a negative assessment by the independent physician and proceed with euthanasia. According to the

Act the physician is responsible, but will have to explain clearly why he or she disregarded the independent physician's assessment (KNMG guideline *Goede steun en consultatie bij euthanasie* ['Good euthanasia support and independent assessment'], para 23).⁶ Page 28 of the Euthanasia Code 2018 notes in this respect that the physician must take the independent physician's opinion very seriously. However, it is not the latter's task to give the physician 'permission'. If there is a difference of opinion between the two, the physician may nevertheless decide to grant the patient's request, but will have to be able to explain that decision to the committee. Another option if there is such a difference of opinion is for the physician to contact a second independent physician who has specific expertise on the issue at hand. In the present case, however, the physician saw no added value in asking a second independent physician for an assessment. Instead, she consulted a colleague at the SLK, a physician. In the committee's view, this physician cannot be considered an independent physician within the meaning of the Act. The physician explained extensively, both orally and in writing, why she proceeded with euthanasia despite the independent physician's negative assessment. She stated, among other things, that the law requires that the physician – rather than the SCEN physician – be satisfied that the patient's suffering is unbearable, with no prospect of improvement. The committee pointed out that pursuant to section 2 (1) (e) of the Act, the independent physician consulted by the physician must without question give his opinion as to whether in the case at hand the due care criteria laid down in section 2 (1) (a) to (d) of the Act have been complied with, including the requirement of unbearable suffering without prospect of improvement. In her explanation the physician indicated, among other things, that she had decided to proceed with euthanasia despite the independent physician's negative assessment because the SLK colleague she consulted shared her view that the patient was suffering unbearably. If the colleague had not shared her view, the physician would not have performed euthanasia. However, the committee found that, besides the fact that the colleague could not be considered an independent physician, the report drawn up by the colleague was very brief and did not explain sufficiently why the colleague thought the patient was experiencing unbearable suffering.

The committee found that the physician had not explained sufficiently why the patient's behaviour as observed by her could be considered to constitute unbearable suffering.

The physician indicated that she thought the care staff were capable, and that they knew the patient's situation and knew how to deal with it.

⁶ The guideline can be found (in Dutch) at www.knmg.nl/advies-richtlijnen/knmg-publicaties/goede-steun-en-consultatie-bij-euthanasie.htm.

According to the physician the care staff were not incompetent, or less competent than the staff of a regular nursing home would be. However, the patient was staying in a small-scale, secure unit of a care home, not in a nursing home equipped for caring for patients in an advanced stage of dementia. The patient's care needs exceeded the level of the care home and made it perfectly reasonable to insist that she be transferred to a specialised institution that was equipped to provide the high level of care required. In the committee's opinion, an option worth considering would have been to transfer the patient to a form of care that was suited to her, where a different approach/protocol/treatment could have achieved some improvement in her situation.

On the basis of the above considerations, the committee found that the physician could not be satisfied that the patient was suffering without prospect of improvement and that there was no reasonable alternative.

NON-COMPLIANCE WITH CRITERIA OF UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT AND THE ABSENCE OF A REASONABLE ALTERNATIVE

For points to consider regarding the absence of a reasonable alternative, see pages 24 ff of the Euthanasia Code 2018.

There is no prospect of improvement if the disease or disorder that is causing the patient's suffering is incurable and the symptoms cannot be alleviated to the extent that the suffering is no longer unbearable. There is also no prospect of improvement if there are no realistic treatment options that may – from the patient's point of view – be considered reasonable, aimed at curing the patient or improving their quality of life (palliative care). It is thus clear that the assessment of the prospect of improvement is closely linked to the question of whether there is a reasonable alternative. This question must be assessed in light of the current diagnosis.

CASE 2017-31

See case 2017-31 on the website for the full text (in Dutch).

FINDING: due care criteria not complied with

KEY POINTS: non-straightforward notification; suffering without prospect of improvement

The patient, a woman in her eighties, had been diagnosed with chronic narrowing of the airways (chronic obstructive pulmonary disease, or COPD) 30 years before her death. She was treated with inhalation medication, but to no effect.

In the final year before her death, the patient was increasingly short of breath, especially if she exerted herself. She refused to be treated with extra oxygen. In addition, since 2002 the patient had been suffering from age-related hearing loss, and since 2014 from loss of appetite after losing her sense of smell and taste. She also experienced some disability due to her fingers being bent. This was partly due to hardening of the skin and partly due to swelling in the tendons causing 'trigger finger' (the finger gets stuck in a flexed position due to inflammation of the tendon sheath and of the tendon, but regularly suddenly straightens again. Injections initially had a positive effect, but after a while they no longer helped.

The patient's suffering consisted of the cumulative effect of all her health issues. Shortness of breath was the main problem, especially if she exerted herself; she could only walk short distances and was severely fatigued. She was also experiencing increasing social isolation. She suffered from the knowledge that in the near future things would only get worse. The patient feared she would no longer be able to drive or to live independently, that she would become dependent on carers and would have to leave her home within the foreseeable future. She dreaded this prospect. Having led a very independent life, the patient experienced her suffering as unbearable. The physician was satisfied that this suffering was unbearable to her, without prospect of improvement according to prevailing medical opinion, and that there were no alternative ways to alleviate her suffering that were acceptable to her.

When the notification was discussed at the committee meeting, questions arose concerning the disorders from which the patient was suffering and which prompted her request for assisted suicide. The committee also wanted to speak with the physician about the options he offered to alleviate the patient's suffering, the fact that the patient was not really open to those options and the physician's response to that.

The physician reported that the patient had been suffering for years from narrowing of the airways (COPD), for which she was treated with inhalation medication. There had been no further diagnostic tests since 1986. In the early stage of her symptoms, the physician suggested several times that he could refer her to a lung specialist for further tests, with a view to making a diagnosis and establishing treatment options. The patient declined.

The patient had already drawn up a euthanasia directive in 2001, and since 2015 she had discussed her wish for euthanasia with the physician many times, and signed new advance directives. The physician never felt forced to carry out her wishes. As he was always used to doing when he received a request for euthanasia, in this situation too he kept searching for alternatives. For instance, he very specifically discussed with her the option of moving into an apartment with no stairs in her immediate neighbourhood. She was only willing to consider this if euthanasia could not be performed because, for instance, an independent physician was of the opinion that not all the statutory due care criteria had been met. Termination of life, however, was what would make her happiest. She resolutely refused an alternative treatment option with extra oxygen.

In view of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well considered, and that she was suffering unbearably. As regards the due care criterion of suffering without prospect of improvement, the committee noted the following.

From the records and the interview with the physician, the committee understood that the main cause of the patient's suffering was shortness of breath that could not be treated satisfactorily. This limited her current and future mobility and independence to such an extent that she had asked the physician for euthanasia on several occasions. In general, the committee expects a physician who receives a request for euthanasia due to suffering that the patient experiences as unbearable to first of all ascertain whether the cause of that suffering has been established and treated adequately. In the present case, the committee likewise expected the physician to ascertain whether the cause of the shortness of breath had been established sufficiently clearly and whether the patient had been treated adequately.

From the records and the physician's further explanation, the committee understood that the patient had suffered from asthma / chronic narrowing of the airways (COPD) for around 30 years. On that basis, the physician treated her with inhalation medication and supported her within the (primary care based) chronic care programme for patients

with chronic narrowing of the airways. Treatment with medication to widen the airways had insufficient effect, if any. Over the years, the physician had the patient undergo various lung function tests. These showed variable exhalation difficulties. This could tie in with asthma/COPD. However, the committee noted that the patient did not respond to the medication she was prescribed on the basis of the working diagnosis of chronic narrowing of the airways (COPD) and that her shortness of breath was becoming worse. This led the committee to doubt whether her shortness of breath was indeed caused by COPD. Although lung function tests may support a suspected diagnosis, they are insufficient to establish a diagnosis of COPD or asthma. That requires further tests by a lung specialist.

Although the physician suggested referring her to a lung specialist several times, in the last two years before her death he did not insist on further specialist medical tests and, in the committee's opinion, was too quick to accept the patient's refusal of further tests.

When it became apparent that patient was not responding to the medication she had been prescribed for years, it would have made sense for the physician to verify whether the patient's shortness of breath could be treated by other means, so that she would no longer experience her suffering as unbearable. However, the physician only sent the patient for an ECG to see if there were any problems with her heart. The results of the ECG did not explain her shortness of breath either.

Taking all the information provided into account, the committee found that the physician did not explore the cause of the patient's shortness of breath sufficiently, was not critical enough with regard to the results of tests carried out within the chronic care programme and had too easily concluded that her suffering was without prospect of improvement. It would have been appropriate for the physician to place more emphasis on the importance of further tests to ascertain the cause of her suffering. The committee found that the physician had not acted in accordance with the statutory due care criterion laid down in section 2 (1) (b) of the Act.

See case 2017-79 on the website for the full text (in Dutch).

CASE 2017-79

FINDING: due care criteria not complied with

KEY POINTS: non-straightforward notification; suffering without prospect of improvement; absence of reasonable alternatives

The patient, a woman in her eighties, was suffering from osteoarthritis, which caused pain in her joints, limbs and back, and impaired movement. These impairments included stiffness, difficulty in walking and repeated falls. As a result, she became less and less self-reliant. In addition she was suspected to have vascular problems, and suffered from oedema and increasing shortness of breath (probably caused by heart failure or a lung disorder combined with long-term high blood pressure). The symptoms had emerged over the years and increased gradually. In the final 18 months before her death the patient experienced increasing disability due to her conditions. She no longer went outside and had fallen several times in the house. After shuffling around briefly, she had to stop and catch her breath. Due to her poor condition, the patient could no longer keep dogs. Dogs meant the world to her, so she experienced her quality of life as being even worse. All the patient could do was read, and sometimes watch television, and in the afternoons she often went to bed.

The patient refused to be examined or treated by specialists. She no longer saw any point in that, on account of her age and life expectancy. She also did not want to be 'messed around with' any more. As her body was becoming increasingly worn out, she refused any aids that would help her mobility. Diuretics could have helped manage her heart failure to an extent, but her mobility would have remained impaired.

Her suffering consisted of her becoming increasingly dependent on other people, to which she was totally opposed. In addition she was often nauseous, she slept badly, and her pain could not always be alleviated adequately. She was an exceptional and very self-willed woman, who had little time for interference from other people. She suffered from the fear of further deterioration, which would ultimately result in her becoming entirely dependent on others. She experienced her suffering as unbearable.

The physician was satisfied that this suffering was unbearable to her and without prospect of improvement according to prevailing medical opinion. According to the physician, there were no alternative ways to alleviate her suffering that were acceptable to the patient.

The patient had discussed euthanasia with her general practitioner several months earlier. The general practitioner, however, was of the opinion that this was a 'completed life issue' and that he should therefore not grant her request for euthanasia. The patient had attempted suicide. She then contacted the SLK.

The SLK physician first visited the patient over a month before her death. On that occasion, the patient asked the physician to actually perform the procedure to terminate her life. She repeated her request during the physician's next two visits. The physician concluded that the request was voluntary and well considered. The physician was convinced that if the patient no longer had any disabilities, she would not have requested euthanasia.

The committee wanted to know how the physician, partly in light of the relatively short time the process took, had come to the conclusion that the patient was suffering unbearably without prospect of improvement.

The physician explained that after speaking with the patient three times and studying the background information, she had gained sufficient insight into the unbearable nature of the patient's suffering. Her situation and the way she was living was at odds with her independent character. Mainly on the basis of the patient's impaired mobility and the impact this had on her life, the physician concluded that the patient was suffering unbearably without prospect of improvement.

The physician indicated she had looked at possible treatment options and had tried to discuss them with the patient. The patient indicated several times that she was completely opposed to being examined or treated. The SLK nurse added that any kind of aid was a bridge too far for the patient. She even refused to discuss using a rollator. The physician was of the opinion that there were no other treatment options available for the patient. When asked about this, the physician indicated that the patient's pain and shortness of breath could possibly have been alleviated by prescribing additional medication. However, as the patient turned down any suggestion of further examination and treatment, the physician did not raise these issues again. The decisive factor for the physician was that there nothing more to be gained in relation to improving the patient's mobility. In the physician's view, the patient had such difficulty walking that she could not have regained her mobility.

The physician pointed out that the independent physician also concluded that there were few treatment options available. The physician contacted the patient's general practitioner by phone, because she wanted to know why the general practitioner could not or would not

help the patient. Unlike the physician, the general practitioner considered that this was a 'completed life issue'. The physician was aware that no further examination had taken place, and agreed that it is difficult when patients refuse to be examined or treated. However, the physician did not want to abandon the patient.

As regards the due care criteria that the physician must be satisfied that the patient is suffering without prospect of improvement and that there must be no reasonable alternative, the committee found as follows. There is no prospect of improvement if the disease or disorder that is causing the patient's suffering is incurable and the symptoms cannot be alleviated to the extent that the suffering is no longer unbearable. This must be determined in the light of whether there are realistic options, other than euthanasia, that would end or alleviate the symptoms. In considering whether there is any realistic prospect of alleviating the symptoms, account must be taken both of the improvement that can be achieved by palliative care or other treatment and of the burden such care or treatment would place on the patient. It is thus clear that the assessment of the prospect of improvement is closely linked to determining whether there is a reasonable alternative. If there are less drastic ways of ending or considerably reducing the patient's unbearable suffering, these must be given preference. The physician and the patient must together arrive at the conclusion that no reasonable alternatives are available to the patient. The perception and wishes of the patient are important. There is an alternative to euthanasia if there is a realistic way of alleviating or ending the suffering which may – from the patient's point of view – be considered reasonable (see the Euthanasia Code 2018, p. 25).

The committee established that the patient was suffering from a range of symptoms. The physician indicated that she tried to discuss available treatment options with the patient, but that she refused any kind of treatment. However, in the committee's opinion it would have been appropriate for the physician – before carrying out the patient's request – to have set the condition that the patient first try some treatment options that were not invasive or burdensome. If a patient refuses any kind of examination and possible treatment of their symptoms, it is impossible to properly assess whether there is any prospect of improvement. It is essential to continue to carefully consider alternatives to euthanasia. In the present case, those possible alternatives were explored insufficiently. For instance, the patient's pain and shortness of breath could possibly have been alleviated by prescribing medication, which might also have improved her mobility. If, after some time, it became clear that there was no improvement, or insufficient improvement, in the patient's situation despite the treatment, the

physician could then have proceeded with euthanasia. The committee considered that although there is no statutory requirement for the physician and the patient to be in a treatment relationship, a physician who is not the patient's attending physician will generally have to argue plausibly that sufficient time was taken to appraise the patient's situation in relation to the statutory due care criteria (see the Euthanasia Code 2018 p. 16). In the present case, however, the physician concluded in a very short space of time that there was no reasonable alternative. The physician did not investigate sufficiently whether there were reasonable alternatives other than euthanasia that would alleviate the patient's symptoms, which might reduce the unbearable nature of her suffering.

The committee is therefore of the opinion that the physician could not be satisfied that there were no other ways to alleviate the suffering and that therefore there was no prospect of improvement.

The physician did not act in accordance with the statutory due care criteria laid down in section 2 (1) (b) and (d) of the Act.

CASE 2017-24
(not included here)

CASE 2017-10
(not included here)

CASE 2017-02
(not included here)

CASE 2017-11
(not included here)
(case similar to 2017-40)

CASE 2017-28
(not included here)

CASE 2017-118
(not included here)

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